



*The Access Center for Independent Living
presents:*

A PARENT & CAREGIVER TRAINING

Fostering Independence

*Supporting our youth and young adults with
disabilities to choose, lead, and thrive.*



What We'll Explore Together

1

Understanding the IL Philosophy

What independence really means and its principles

2

The Parent's Changing Role

Moving from protector to partner over time

3

Building Independence & Self-Advocacy

Person-centered planning and everyday skills

4

Disability Rights & Transition

Laws, transition, and decision-making support

5

Community Resources & Supports

Services, connection, and caregiver wellbeing

6

Action Planning for Independence

Building your family's plan and next steps

GETTING STARTED

Making This Space Work for Everyone

A few shared agreements so every family feels welcome, safe, and heard.

1

Respect & Confidentiality

What's shared here stays here. Every family's story and situation is honored.

2

Strengths First

We speak about our children in terms of what they can do and can learn.

3

No Wrong Questions

Ask anything. If you're wondering it, another parent likely is too.

4

Access For All

Need a break, larger text, captions, or a quieter moment? Just ask.

5

Share The Air

Everyone's voice matters. We make room for many perspectives.

6

Progress, Not Perfection

Small steps count. We celebrate effort and growth, not flawless outcomes.

Why We're Here Today

This training exists because families are the most powerful force in a young person's independence.

01

The Purpose

To help you support your child's independence while keeping safety and dignity in balance.

02

What You'll Gain

A shared language, practical strategies, and confidence to become your child's partner in growth.

03

How It Works

Short teaching bursts, real family scenarios, reflection prompts, and group discussion opportunities throughout.

What This Training Is and Is Not

This Training Is Not About:

- Removing support from your child
- Expecting everyone to live independently
- Ignoring legitimate safety concerns
- Pretending disability-related barriers don't exist
- Making parents feel guilty
- Expecting independence to look the same for everyone

It IS About:

- Increasing choice
- Building skills
- Supporting self-determination
- Removing barriers
- Creating opportunities
- Respecting the person's voice
- Finding the right level of support

What You'll Be Able To Do

1

Define Independent Living

Explain what the IL philosophy means and why it's about choice and control — not doing everything alone.

2

Recognize the Core Principles

Identify consumer control, self-determination, dignity of risk, equal access, peer support, and presuming competence.

3

Challenge Limiting Myths

Spot and reframe common myths about disability and independence in everyday life.

4

Picture the Path Forward

Use the Independence Ladder to see how responsibility transfers gradually over time.



MODULE 1

Understanding the Independent Living Philosophy

What independence really means — and the principles behind it.



MODULE 1 · CORE CONCEPT

What Independent Living Really Means

“Independence is about control over your life — not doing everything by yourself.”

- It means having choice and a say in decisions that affect you.
- It means directing your own supports — asking for and accepting help is part of independence, not the opposite of it.
- It means being included and valued in your community.
- Everyone — with or without a disability — relies on others. Interdependence is normal and healthy.

Common Myths About Independence

The Myth

- “Independence means doing everything alone.”
- “My child isn't ready — maybe someday.”
- “It's safer if I just do it for them.”
- “Needing support means they can't be independent.”

The Reality

- Independence means having control and direction, with whatever support is needed.
- Skills grow through practice now — waiting for 'ready' delays the growth that creates readiness.
- Doing for reduces confidence; doing with builds it. Over-help can be its own risk.
- Using support to reach your goals is exactly what self-directed independence looks like.

*Reframing these beliefs is the first and most important step toward **partnership**.*

What Shapes Our View of Independence?

Parents and caregivers may develop beliefs about independence based on:

- How they were raised
- Cultural and family expectations
- Advice from professionals
- Past safety concerns
- Their child's diagnosis or support needs
- Fear of judgment from others
- Previous experiences of failure or discrimination

Can you think of any other beliefs to add to the list?

Do you believe our beliefs influence the opportunities we give our children?

What experiences have shaped the way you view your child's independence?

MODULE 1 · FOUNDATIONS

Choice, Control, Dignity & Inclusion

Four everyday freedoms that make a life feel like your own.

- Choice — having real options and a voice in decisions, big and small.
- Control — directing your own routines, supports, and goals.
- Dignity — being treated as a capable, respected adult.
- Community inclusion — belonging, contributing, and being part of everyday life.



Real Choice vs. Limited Choice

Real Choice

- The options are meaningful.
- The young person understands the choices.
- Their preference is respected.
- They are allowed to say no.
- Support is provided without taking control.

Limited Choice

- The decision has already been made.
- Only one acceptable answer is offered.
- The parent chooses based on convenience.
- The young person is pressured to agree.
- Their answer is ignored.

Example:

“Would you like to wear the blue shirt or the red shirt?” is a choice.

“You’re wearing the blue shirt, okay?” is not.

Your Child Is Watching You

Children often learn independence by watching the adults around them.

Your child notices:

- How you solve problems.
- Whether you ask for help when you need it.
- How you respond when mistakes happen.
- Whether you stay calm during challenges.
- How you advocate for yourself.
- Whether you believe they are capable of learning and growing.
- Everyday interactions teach lessons about confidence, resilience, and independence.

Children learn as much from what we model as they do from what we teach.

Reflection

What messages about independence might your child be learning simply by watching you?

The Core Principles of Independent Living

Six principles guide the independent living movement. We'll explore each one.

1

Consumer Control

People with disabilities lead the decisions and services that affect their lives.

2

Self-Determination

The right to set your own goals and direct your own path.

3

Dignity of Risk

The freedom to take chances, try, and even fail — and grow from it.

4

Equal Access & Opportunity

Removing barriers so everyone can participate fully.

5

Peer Support

Learning and gaining strength from others with shared experience.

6

Presuming Competence

Assuming capability first, and providing support to demonstrate it.

Consumer Control

The person leads decisions about their own life.

Individuals should have the greatest voice in:

- Their daily routines
- Their goals
- Their services and supports
- Where and how they live
- Education and employment choices
- Healthcare decisions
- Community participation

What This Can Look Like at Home

- Asking before making decisions for them
- Offering meaningful choices
- Including them in family conversations
- Allowing them to direct how help is provided
- Respecting preferences that may differ from yours

Parent Reflection: Where could your child have more control over a decision that currently belongs mostly to you?

Self-Determination

The right and ability to direct your own path.

Self-determination includes:

- Making choices
- Setting personal goals
- Solving problems
- Expressing preferences
- Understanding consequences
- Asking for support
- Learning from experience

These skills develop through practice over time.

Families Can Support Self-Determination By:

- Letting youth choose goals that matter to them
- Asking what they want before offering solutions
- Teaching decision-making step by step
- Allowing them to change their mind
- Helping them reflect on what worked and what did not

Key Message: Young people cannot learn to direct their lives if they rarely get opportunities to make decisions.

Dignity of Risk

The right to try, make mistakes, and learn.

Every person needs opportunities to:

- Take reasonable chances
- Experience natural consequences
- Learn from mistakes
- Build confidence
- Discover their own limits
- Develop resilience

Without Reasonable Risk, Youth May Miss Chances To:

- Practice problem-solving
- Build judgment
- Gain confidence
- Learn safety skills
- Experience pride and accomplishment

Parent Question: Am I preventing genuine danger—or preventing discomfort, frustration, or an imperfect result?

Protection should reduce serious harm, not remove every opportunity for growth.

Equal Access and Opportunity

Remove barriers instead of lowering expectations.

Barriers may be:

- Physical
- Communication-related
- Attitudinal
- Financial
- Technological
- Transportation-related
- Informational
- Program or policy-based

Equal Access May Include:

- Ramps or accessible entrances
- Captions or interpreters
- Visual instructions
- Assistive technology
- Extra processing time
- Accessible transportation
- Flexible communication options
- Reasonable accommodations

Key Message: The disability is not always the main barrier. Sometimes the environment, system, or attitude is what prevents participation.

Discussion: What barrier could be removed to help your child participate more fully?

Peer Support

Learning from people with shared lived experience.

Peer support connects youth to others who can:

- Share practical advice
- Model independence
- Build confidence
- Reduce isolation
- Offer encouragement
- Help them understand disability identity
- Show what is possible

Parents and caregivers can also benefit from connecting with other families.

Peer Support Can Happen Through:

- Centers for Independent Living
- Youth groups
- Disability organizations
- Mentoring programs
- Support groups
- Online communities
- Social and recreational activities

Key Message: Professionals can provide information. Peers can often provide understanding, connection, and lived experience.

Presuming Competence

Begin with the belief that the person can learn, understand, and contribute.

Presuming competence means:

- Assuming ability before assuming inability
- Speaking directly to the person
- Providing enough time to respond
- Offering accessible information
- Teaching skills before deciding they cannot
- Recognizing communication in many forms
- Keeping expectations high while providing support

It Does Not Mean:

- Ignoring disability-related needs
- Expecting someone to perform without support
- Pretending a task is easy
- Removing accommodations
- Denying real challenges

Key Message: Support needs should guide how we teach—not determine whether we believe growth is possible.

Presuming Competence in Practice

Shift the internal question from doubt to support.

Instead of Thinking:

- *“They probably won’t understand.”*
- *“They can’t make that decision.”*
- *“It will be too difficult.”*
- *“I should speak for them.”*
- *“They are not ready.”*

Try Asking:

- *“How can I explain this more clearly?”*
- *“What support would help them choose?”*
- *“Can this be broken into smaller steps?”*
- *“How can their voice be included?”*
- *“What opportunity would help them become ready?”*

Remember: Presuming competence does not mean assuming a person needs no help.

It means refusing to let assumptions become permanent limits.

Learned Dependence

Sometimes dependence develops because opportunities to practice independence were limited.

Learned dependence may look like:

- Waiting for someone else to make decisions.
- Frequently saying "I can't" before trying.
- Looking to adults for every answer.
- Avoiding new experiences.
- Giving up quickly after mistakes.
- Feeling anxious about making choices.

Families Can Help By:

- Offering meaningful choices every day.
- Allowing extra time to complete tasks.
- Encouraging problem-solving before stepping in.
- Celebrating effort rather than perfection.
- Gradually transferring responsibility.

Key Message

The goal is not to remove support.

The goal is to provide support that builds confidence instead of replacing independence.

Control, Self-Direction & the Dignity of Risk

1

Consumer Control — they hold the remote

Your child, not the system or the parent, leads the choices. Example: choosing which chores, hobbies, or supports fit their life.

2

Self-Determination — their goals, their path

Support the goals they care about, even if different from yours. A motivated goal is pursued; an imposed one is resisted.

3

Dignity of Risk — the right to try

Overprotection removes the chance to learn. Taking a bus, managing money, or handling a mistake builds real competence.

Access, Peer Support & Presuming Competence

4

Equal Access & Opportunity

Barriers — physical, attitudinal, or informational — are the problem, not the person. We remove barriers instead of lowering expectations.

5

Peer Support

Connection with others who share lived experience builds confidence, role models, and belonging for both youth and parents.

6

Presuming Competence

Start by assuming your child can, then teach and support. Low expectations become self-fulfilling; high, supported expectations lift outcomes.

IL Principles in Everyday Family Life

IL Principle	What It Can Look Like At Home
Consumer Control	Your child helps decide their schedule and goals.
Self-Determination	Your child chooses activities based on their interests.
Dignity of Risk	Your child is allowed to try tasks that may not go perfectly.
Equal Access	Barriers are removed so your child can participate.
Peer Support	Your child connects with others who share lived experience.
Presuming Competence	You begin with the belief that your child can learn.

Discussion:

Which principle is already strong in your family? Which one needs more attention?

Independence vs. Dependence — a False Choice

An Either/Or Trap

- “Either they do it alone or they can't do it.”
- Help is seen as the opposite of independence.
- Support is something to outgrow completely.
- Value is measured by how little help is used.

Interdependence — the Real Goal

- Everyone gives and receives support throughout life.
- Directing your own support IS independence.
- The goal is the right support, not zero support.
- Value comes from choice, contribution, and connection.

We're not choosing between independent and dependent — we're building interdependence.

What Success Really Looks Like

Independence looks different for every person.

Success is not measured by whether someone:

- Lives completely alone.
- Drives a car.
- Has a traditional full-time job.
- Needs no support.

Success is measured by whether a person:

- Makes meaningful choices.
- Has relationships and community.
- Directs their own supports.
- Contributes in ways that matter to them.
- Continues learning and growing.
- Lives a life that reflects their own goals.

Key Message

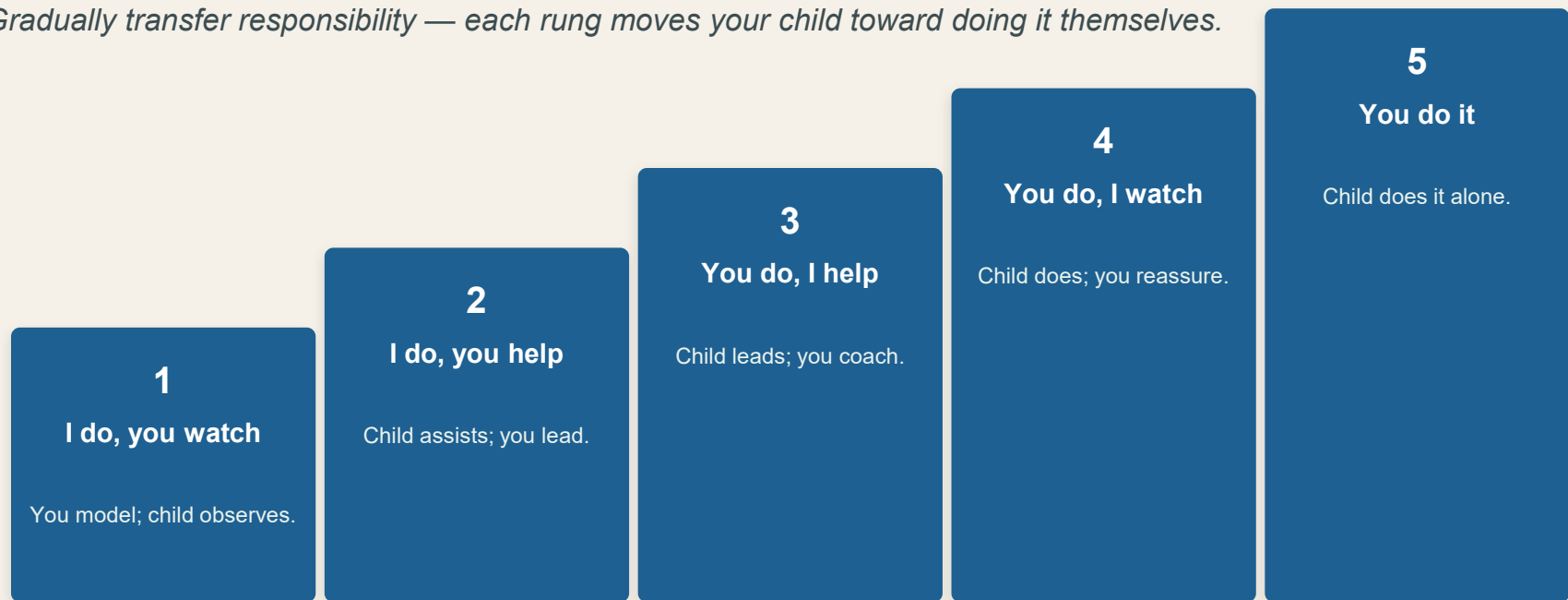
Independent Living is about self-direction—not fitting one picture of adulthood.

Discussion

How has your definition of success changed as your child has grown?

The Independence Ladder

Gradually transfer responsibility — each rung moves your child toward doing it themselves.



Increasing independence over time

Independence Doesn't Start At 18

Independence develops through hundreds of small experiences across childhood.

Age:

Preschool

Elementary

Middle School

High School

Young Adult

Opportunities To Build Independence:

- Choose clothing, toys, or snacks
- Help clean up, pack a backpack, prepare simple snacks
- Complete chores, organize homework, begin managing routines
- Practice transportation, budgeting, appointments, and self-advocacy
- Manage services, employment, education, healthcare and long-term goals

Key Message:

Every stage prepares for the next. The best preparation for adulthood begins years before adulthood arrives.

Picture Independence for Your Child

Take a quiet moment to reflect and jot a few notes. There are no wrong answers.

- What is one responsibility your child may be ready to begin practicing now?
- When you imagine your child living their most independent life, what do you see?
- Which core principle — control, self-determination, dignity of risk, access, peer support, or presuming competence — feels hardest for your family right now?
- What is one belief about independence you'd like to reframe after this module?

Small-Group Discussion

In groups of 3-4, share as much as you're comfortable with.

- Share one myth about independence you've encountered — from others or yourself.
- Describe a moment your child surprised you by doing more than expected.
- What's one small opportunity for choice or control you could offer this week?
- Choose a spokesperson to share one insight with the whole group.

Module 1 — Key Takeaways

- ✓ Independent living means choice and control, not doing everything alone.
- ✓ Interdependence — giving and receiving support — is the real goal.
- ✓ Six principles anchor the philosophy, from consumer control to presuming competence.
- ✓ Dignity of risk gives young people the right to try, learn, and grow.
- ✓ Reframing myths is the first step toward partnership.

KEY TAKEAWAY

Start by assuming your child can — then support them to show it.



MODULE 2

The Parent's Changing Role

Moving from protector to partner as your child grows.

MODULE 2 · THE SHIFT

From Protector to Partner

Your love doesn't shrink — its expression changes.

- Protector: I keep my child safe by managing the world for them.
- Partner: I prepare my child to manage the world with growing skill.
- The goal shifts from doing for to doing with, then cheering on.
- You remain deeply involved — as coach, ally, and biggest supporter.



Why Stepping Back Can Feel So Hard

Naming the fear is the first step to planning around it.

Parents may hesitate to step back because of:

- Fear that their child will fail
- Fear of injury or exploitation
- Past emergencies
- Lack of accessible community options
- Worry that others will not be patient
- Guilt about allowing discomfort
- A habit of being the primary problem-solver
- Concern about being viewed as an uncaring parent

Key Message: Fear is understandable—but fear should lead to planning, not automatic restriction.

Common Barriers To Independence – and What Helps

Common Barrier

- Fear of failure
- Safety concerns
- Doing tasks is faster
- Low confidence
- Communication barriers
- Difficulty organizing tasks
- Limited community access
- Parent uncertainty

Helpful Response

- Begin with low-risk practice and small steps
- Assess the actual risk and create a safety plan
- Use the Independence Ladder and allow extra time
- Build small successes and praise effort
- Use accessible communication and provide wait time
- Use checklists, timers, routines, and visual supports
- Identify accommodations, transportation, and local resources
- Use peer support, CIL services, and professional guidance

Key Message: Barriers should lead to additional support and problem-solving—not lower expectations.

Supporting Independence While Keeping Safety

Safety and independence are partners, not opposites. We plan for both.

1

Assess The Real Risk

Ask what could actually go wrong, how likely, and how serious — not just what feels scary.

2

Teach & Scaffold

Build the skill and safety plan together before stepping back. Practice in low-stakes settings first.

3

Adjust The Support

Offer just enough help — and remove it as competence grows. Revisit and refine.

Helping vs. Overprotecting

Overprotecting

- Stepping in before they've tried.
- Answering and speaking for them.
- Removing all obstacles and choices.
- Sends the message: "I don't think you can."

Helpful Support

- Waiting, then offering help if asked.
- Prompting them to speak for themselves.
- Letting them navigate manageable challenges.
- Sends the message: "I believe you can, and I'm here."

The difference is often just a few seconds of patience — the pause that lets them try.

When Helping Becomes Overhelping

Support should build ability, not replace it.

Helping may become overhelping when we:

- Complete a task before the young person has tried.
- Speak for them when they can communicate.
- Correct every mistake.
- Make decisions without asking their opinion.
- Avoid teaching because doing it ourselves is faster.
- Assume frustration means the task should stop.
- Remove every challenge or natural consequence.

Ask Yourself: Am I helping my child complete this task—or helping them learn how to complete it?

Building Confidence Through Opportunities

Confidence isn't given — it's grown through real experiences of success.

1

Create Chances To Succeed

Offer tasks slightly beyond current comfort, with support ready. Success builds belief.

2

Notice & Name Effort

Praise the trying and the strategy, not just the result. Effort is repeatable.

3

Let Them Own The Win

Resist redoing or correcting. A 'good enough' job done by them beats a perfect one done for them.

4

Stack Small Successes

Each success becomes evidence they can point to next time fear shows up.

Encouraging Age-Appropriate Decision-Making

Decision-making is a skill — it grows with practice and increasing stakes.

1

Start Small & Real

Offer everyday choices: meals, clothes, how to spend time or money.

2

Widen The Circle

Move toward bigger decisions: schedules, goals, health, and relationships.

3

Talk It Through

Coach the thinking: options, pros and cons, and 'what might happen if...'.

The Choice-Building Continuum

1

Begin With Simple Choices

- What to wear
- What snack to eat
- Which activity to do
- What music to play

2

Move Toward Shared Decisions

- How to organize a schedule
- What responsibilities to take on
- Which goals to pursue
- What support is helpful

3

Prepare for Adult Decisions

- Employment
- Education
- Healthcare
- Relationships
- Housing
- Money management

Key Message: Decision-making skills are built through years of practice.

Mistakes, Natural Consequences & Safe Risk

Let Them Learn From

- Forgetting homework or an item they needed.
- Spending their money and running short.
- A social misstep and repairing it.
- A task done imperfectly the first time.

Step In To Prevent

- Anything with serious injury or health risk.
- Situations involving exploitation or abuse.
- Legal jeopardy or lasting harm.
- Risks the young person can't yet understand.

Natural consequences teach; unsafe risks require protection. Learn to tell them apart.

Risk Assessment Questions for Parents

Trade automatic reaction for a quick, honest assessment.

Before stepping in, ask:

- What could realistically happen?
- How likely is it to happen?
- How serious would the outcome be?
- Does my child understand the risk?
- Can we reduce the risk through teaching or support?
- Can this be practiced in a safer environment?
- Am I responding to danger—or to my own discomfort?

Key Message: The goal is not to remove all risk.

The goal is to make risk understandable and manageable.



MODULE 2 · STRATEGY

Coaching Instead of Rescuing

A coach doesn't play the game for you — they prepare you to play it well.

- Ask before advising: “What have you thought about trying?”
- Guide with questions, not takeovers.
- Let them attempt the play; debrief afterward.
- Be the steady voice on the sideline, not the one on the field.

Coaching Questions Parents Can Use

Guide the thinking instead of handing over the answer.

Instead of immediately giving the answer, ask:

- What do you think happened?
- What have you tried so far?
- What are your options?
- What might happen with each choice?
- What do you think you should do first?
- Would you like help, a suggestion, or more time?
- Who could you ask for support?
- What would you do differently next time?

Key Message: Good questions help young people build their own problem-solving process.

Family Communication Strategies

How we talk shapes whether young people feel capable and heard.

1

Listen First

Seek to understand before advising. Reflect back what you hear.

2

Use Strengths Language

Speak about your child in terms of ability and growth, especially in front of them.

3

Offer, Don't Impose

"Would you like help or ideas?" respects their autonomy.

4

Repair & Revisit

Disagreements are normal. Come back, apologize when needed, and keep the door open.

Independence Grows Through Everyday Conversations

Small changes in how we speak can build confidence and self-determination.

Instead of:

- “Let me do that for you.”
- “Be careful!”
- “You can’t.”
- “I’ll ask for you”

Try:

- “Would you like help, or would you like to try first?”
- “What’s your plan to stay safe?”
- “Let’s figure out how.”
- “Would you like to ask, or would you like me to help you practice first?”

Key Message: Words can either encourage dependence—or build confidence.

REFLECTION

~5 minutes

Where Am I on the Protector-to-Partner Path?

Reflect honestly and kindly with yourself.

- In what area are you still mostly 'protector,' and what makes stepping back hard there?
- Where have you already become a 'partner,' and what helped you get there?
- What is one 'rescue' you could turn into a 'coaching' moment this week?

Parent Role-Play: Coach, Don't Rescue

In pairs, take turns as the parent and the young adult. Practice responding as a coach.

- Scenario A: Your 17-year-old forgot to charge their communication device before an outing.
- Scenario B: Your young adult wants to take the city bus alone for the first time.
- Scenario C: Your teen spent their monthly money in one week and wants more.
- Debrief: How did coaching feel different from rescuing? What was hard?

Module 2 — Key Takeaways

- ✓ The parent role evolves from protector to partner — love stays, its form changes.
- ✓ Safety and independence are planned together, not traded off.
- ✓ The pause before helping is where independence grows.
- ✓ Natural consequences teach; only unsafe risks require stepping in.
- ✓ Coach with questions instead of rescuing with solutions.

KEY TAKEAWAY

Do with, not for — then cheer them on.



MODULE 3

Building Independence & Self-Advocacy

Person-centered planning and everyday skill-building.

MODULE 3 · FOUNDATION

Person-Centered Planning

The person is the author of the plan — everyone else helps write it down.

- Plans start with the young person's own vision, preferences, and goals.
- Let youth lead the conversation; support communication however they express it.
- Focus on 'What matters to them,' not only 'What's the matter.'
- Family and professionals surround and support the person's direction.



What Matters TO vs. What Matters FOR

Two lenses that must work together in good planning.

What Matters To the Person

- People they enjoy
- Activities they value
- Their routines and preferences
- Their dreams and goals
- What makes them feel comfortable
- What gives their life meaning

What Matters For the Person

- Health
- Safety
- Needed supports
- Medical care
- Legal requirements
- Protection from abuse or exploitation

Key Message: Good planning balances both—but the person's voice must remain central.

Focusing on Strengths & Interests

We build independence on what a young person can do and loves to do.

1

Name The Strengths

List talents, skills, and positive traits. Ask others who know them well.

2

Follow The Interests

Passions are motivation. Goals tied to interests get pursued.

3

Connect To Goals

Turn strengths and interests into real roles, activities, and next steps.

Strengths Can Become Opportunities

When we focus on strengths, we help young people discover purpose, confidence, and future possibilities.

Strength or Interest

- Enjoys helping others
- Loves technology
- Creative or artistic
- Organized
- Enjoys animals
- Likes cooking

Possible Opportunities

- Peer mentoring, volunteering, customer service
- Computer support, coding, graphic design
- Art, photography, marketing, design
- Office support, inventory, scheduling
- Animal care, pet grooming, veterinary support
- Food service, catering, culinary training

Key Message: Strengths are often the foundation for employment, community involvement, and lifelong confidence.

Reflection: What is one strength your child has that could be developed into a future opportunity?

Moving Beyond Deficit-Based Thinking

Change the question, and you change what you see.

Deficit-Based Question

“What can’t my child do?”

Strengths-Based Questions

- What can my child already do?
- What are they interested in learning?
- What motivates them?
- What support helps them succeed?
- What environments bring out their strengths?
- What skills can be built from their interests?

Example: Instead of: “She struggles socially.”

Try: “She communicates best in small groups and enjoys structured activities.”

Setting Goals That Matter

Good goals are the young person's own — clear, meaningful, and reachable in steps.

1

Owned By Them

The young person chooses the goal; motivation follows ownership.

2

Specific & Visible

Define what success looks like so progress can be seen and celebrated.

3

Broken Into Steps

Turn a big goal into small, doable actions along the Independence Ladder.

4

Reviewed & Adjusted

Revisit regularly. Celebrate progress; adjust the plan, not the person.

Parent Goal or Youth Goal?

The same future, approached from two very different starting points.

Parent-Directed Goal

"I want my son to work in food service because there are openings nearby."

Youth-Directed Goal

"I want to work with animals because I feel calm and confident around them."

Person-Centered Approach

Explore jobs involving animals, identify needed skills, and build steps toward meaningful employment.

Discussion: How can families share concerns without replacing the young person's goal?

Teaching Decision-Making Skills

This is a repeatable process young people can use for choices big and small.

1

Name the decision

What exactly are you choosing? Put it into words together.

2

List the options

Brainstorm possibilities, including ones they might not have considered.

3

Weigh pros and cons

What's good and not-so-good about each? What might happen?

4

Choose, act, and reflect

Make the call, try it, then review: what worked, what you'd change.

Teaching Communication Skills

Every person communicates — our role is to recognize, honor, and support the development of their voice.

1

Honor All Voices

Speech, devices, signs, pictures, gestures — all are valid communication.

2

Practice Real Talk

Rehearse asking for help, ordering food, greeting, and expressing needs.

3

Give Wait Time

Pause and let them respond. Resist finishing sentences for them.

Communication Is More Than Speech

Speech is one channel among many—look for all of them.

A person may communicate through:

- Spoken words
- Sign language
- Communication devices
- Pictures or symbols
- Writing or typing
- Facial expressions
- Body language
- Gestures
- Behavior

Important: *Facial expressions, body language, eye contact, movement, and behavior may be influenced by disability. Avoid assuming you know what a person is thinking or feeling based on nonverbal cues alone.*

Respectful Communication

The language we use matters. The words we choose influence expectations, confidence, and self-identity.

Instead of saying:

- “They suffer from a disability.”
- “My special needs child...”
- “They cant...”

Consider:

- “They have a disability.”
- “My son” or “My daughter” or “My child”
- “They are still learning”

Instead of speaking for your child automatically, give them the opportunity to speak first.

Also Remember: Language preferences vary. Whenever possible, respect how the person chooses to describe themselves and their disability. This is important because neither person-first nor identity-first language should be presented as universally correct.

Key Message: Respectful language promotes dignity, autonomy, and high expectations.

Reflection: How can small changes in language encourage greater independence?



MODULE 3 · SELF-ADVOCACY

Growing Self-Advocacy

Self-advocacy is knowing what you need — and being able to ask for it.

- Know yourself: strengths, needs, and what helps.
- Know your rights and accommodations.
- Speak up: ask questions, express preferences, say 'no.'
- Practice in safe settings first, then real ones — appointments, school, work.

Preparing Others To Support Your Child

Advocacy doesn't stop with parents—it extends to everyone involved in your child's life.

Help others understand:

- How your child communicates.
- Their strengths and interests.
- Accommodations that are helpful.
- Ways to encourage independence instead of doing tasks for them.
- How to include your child in conversations and decisions.
- The importance of speaking directly to your child whenever possible.

People you may need to educate:

- Grandparents
- Extended family
- Babysitters
- Teachers
- Coaches
- Employers
- Faith communities
- Friends and neighbors

Key Message: The more people who support independence, the more opportunities your child has to practice it.

Discussion: Who is one person in your child's life that could better support their independence?

The Building Blocks of Self-Advocacy

Four skills that grow together over time.

1

Know Yourself

- My strengths
- My needs
- My preferences
- What helps me succeed

2

Know Your Rights

- Accessibility
- Accommodations
- Respect
- Equal opportunity

3

Communicate

- Ask questions
- Express choices
- Request support
- Say no
- Report concerns

4

Take Action

- Participate in meetings
- Solve problems
- Follow up
- Ask for changes

Building Problem-Solving Skills

When something goes wrong, a young person who can problem-solve stays independent.

1

Spot The Problem

Notice and name what's not working, calmly and specifically.

2

Generate Options

Think of a few possible solutions before acting.

3

Try & Evaluate

Pick one, try it, and check whether it worked.

4

Ask For Help Wisely

Knowing when and how to seek help is a problem-solving skill, not a failure.

Rights & Responsibilities

Rights

- To make choices about your own life.
- To reasonable accommodations and access.
- To be treated with dignity and respect.
- To take risks, try, and learn.

Responsibilities

- To communicate needs and preferences.
- To follow through on commitments.
- To respect others and shared rules.
- To learn from outcomes and keep growing.

Adulthood pairs rights with responsibilities — we teach both together.

Teaching Responsibility Without Removing Support

Build responsibility on a foundation of support, not instead of it.

Responsibility can be taught by helping young people:

- Complete household tasks
- Keep track of schedules
- Prepare for meetings
- Communicate when they need help
- Follow through on agreed-upon steps
- Repair mistakes
- Respect shared spaces and boundaries
- Understand how choices affect others

Key Message: Responsibility should be taught gradually—not demanded without preparation.

Participating in IEP, Appointments & Planning Meetings

Meetings about a young person work best when the young person is at the table.

1

Prepare Together

Review the agenda, list goals, and practice what they want to say beforehand.

2

Let Them Lead

Have them open the meeting, share goals, or run part of the agenda.

3

Debrief After

Talk through what happened, what they advocated for, and next steps.

Executive Functioning and Independence

Understanding a task and managing it are different skills.

May understand a task but struggle with:

- Starting the task
- Remembering steps
- Staying focused
- Managing time
- Organizing materials
- Adjusting when plans change
- Completing the task independently

Helpful supports may include:

- Visual schedules
- Timers
- Checklists
- Phone reminders
- Labels
- Color coding
- Step-by-step instructions

Key Message: Using tools is not dependence. Tools support independence.

MODULE 3 · HOME

Daily Living Skills

Independence is built one everyday task at a time.

- Cooking, cleaning, laundry, and personal care.
- Money: budgeting, paying, and saving.
- Time: schedules, alarms, and appointments.
- Health: medication, hygiene, and appointments.



Independence Isn't Linear

Progress rarely happens in a straight line.

Growth often includes:

- Trying something new.
- Experiencing setbacks.
- Learning from mistakes.
- Building confidence.
- Trying again with greater success.
- Continuing to grow over time.

Remember: *Temporary setbacks do not erase progress. Learning takes practice, patience, and perseverance.*

Some days will feel easier than others—and that's okay.

Key Message: Growth is measured over time, not by one difficult day.

Reflection: Think of a skill your child has learned over time. What setbacks did they overcome along the way?

Independence at Home

Home is the safest, richest classroom for practicing independence.

1

Share The Chores

Give real, meaningful responsibilities that contribute to the household.

2

Use Visual Supports

Checklists, labels, and routines make independence repeatable.

3

Build Routines

Predictable morning and evening routines lower stress and grow autonomy.

4

Let Them Own A Space

A zone or task that's fully theirs to manage builds pride and skill.

Everyday Opportunities to Practice Self-Advocacy

Self-advocacy is learned through everyday experiences—not just major life decisions.

Encourage your child to practice by:

- Ordering their own meal at a restaurant.
- Asking a teacher or supervisor a question.
- Scheduling or checking in for appointments.
- Introducing themselves to new people.
- Requesting an accommodation when needed.
- Expressing opinions during family decisions.
- Solving small problems before asking for help.

Key Message: Confidence grows through repeated opportunities to use one's voice.

Family Challenge: Choose one new opportunity this week for your child to practice speaking up or making a decision independently.

REFLECTION

~5 minutes

One Skill, One Step

Reflect on where to focus next.

- What is one daily living or self-advocacy skill your child is ready to grow?
- Which rung of the Independence Ladder are you on for that skill today?
- What is the very next small step to move up one rung?

Case Study — Maya Wants a Job

Read together, then discuss in small groups.

- Maya, 19, loves animals and is great with routines. She wants a job but has never interviewed. Her parents worry she'll be turned down.
- Which of Maya's strengths and interests could guide a job goal?
- How could person-centered planning and self-advocacy help Maya lead her own job search?
- What's one 'coaching, not rescuing' move her parents could make this week?

Module 3 — Key Takeaways

- ✓ Person-centered planning puts the young person in the author's seat.
- ✓ Build on strengths and interests, not deficits.
- ✓ Decision-making, communication, and problem-solving are teachable processes.
- ✓ Self-advocacy — knowing needs and asking for them — is a cornerstone skill.
- ✓ Daily living skills grow one rung and one task at a time.

KEY TAKEAWAY

Teach the skill, then hand over the pen.



MODULE 4

Disability Rights & Transition to Adulthood

Laws, transition planning, and decision-making support.

Landmark Disability Rights Laws

Three laws form the foundation of disability rights in the United States. These laws are important for parents and caregivers to know and be familiar with.



Americans with Disabilities Act

Prohibits discrimination and requires access in employment, public life, and services.



Individuals with Disabilities Education Act

Guarantees eligible students a free appropriate public education (FAPE) through an IEP while they remain eligible under IDEA.



Section 504

Bars disability discrimination in programs that receive federal funds; provides accommodations.

Teaching Your Child About Disability Rights History

Knowing where our rights came from can help young people understand why their voices matter.

Disability rights were not simply given—they were advanced through decades of advocacy by people with disabilities, families, and allies.

Teaching this history can help young people:

- Understand that disability is part of a larger community and history.
- Recognize that accessibility and accommodations are rights, not favors.
- Develop pride and a positive disability identity.
- Understand why self-advocacy matters.
- See people with disabilities as leaders and changemakers.
- Recognize that their own voice can create change.

Keep It Simple and Interesting

Parents don't have to teach a history class!

Try these suggestions:

Tell the Story

Share short stories about disability rights leaders and what they changed.

Use Videos & Photos

Watch age-appropriate clips about the Disability Rights Movement, the 504 Sit-In, Capitol Crawl, and passage of the ADA.

Connect History to Everyday Life

When you see a ramp, accessible parking space, captioning, or accommodation, talk about why that access exists.

Meet Disability Leaders

Attend CIL events, disability organizations, advocacy groups, or peer programs where youth can meet adults with disabilities.

Celebrate Disability History

Recognize Disability Pride Month, the ADA anniversary, and important disability rights milestones.

Key Message: Knowing disability history helps young people understand: "People like me helped create change—and my voice matters too."

Reflection: How could you begin making disability history part of your family's conversations?

Make Disability History Come Alive

Turn history into conversations your child can connect to.

Try these suggestions:

See a curb cut?

Ask: "Did you know people had to advocate for communities to become more accessible?"

Use captions?

Explore how disability advocacy helped expand communication access.

Learning about the ADA?

Watch footage from the Capitol Crawl and talk about why activists took action.

Requesting an accommodation?

Connect it to the people who fought for equal access.

Visiting your CIL?

Ask about local disability advocates and the Independent Living Movement in your community.

Try asking your child questions like:

What barrier would you change?

What does accessibility mean to you?

What right is most important in your life?

If you could make your community more accessible, what would you change?

How could you advocate for that change?

Key Message: History becomes meaningful when young people can see themselves in it.

Help Your Child Understand Their Own Disability

Self-advocacy begins with understanding yourself.

Self-advocacy begins with understanding yourself.

As appropriate for their age and development, help your child understand:

- The name of their disability or disabilities.
- How their disability affects them personally.
- Their individual strengths.
- Areas where they may need support.
- Accommodations and tools that help them.
- How to explain their needs to others.
- That having a disability is nothing to be ashamed of.
- That they have rights and a voice in decisions affecting them.

Move From:

"Mom knows what accommodations I need." to

"I know what helps me learn, and I can explain it."

Practice Statements to do with your child:

"I have difficulty with ____."

"It helps me when ____."

"I use ____ to help me."

"I need ____ in order to participate."

"I would like to request ____."

Key Message: It is difficult to advocate for needs you have never been taught to understand or describe.

Accessibility & Accommodations

Accommodations remove barriers so a person can show what they can do.

1

What They Are

Adjustments — tools, time, formats, or supports — that provide equal access.

2

Examples

Extended time, screen readers, ramps, captions, flexible schedules, quiet spaces.

3

How To Get Them

Request through school, college disability services, or an employer; document the need.

4

Self-Advocacy Link

Young adults increasingly request their own accommodations — practice this now.

Accommodation or Modification?

Two different tools that are often confused.

Accommodation

Changes how a person accesses or completes a task.

Examples:

- Extra time
- Captions
- Screen reader
- Quiet workspace
- Written instructions

Modification

Changes what a person is expected to learn or complete.

Examples:

- Simplified assignments
- Reduced learning standards
- Different curriculum content

Key Message: Both may be appropriate, but they serve different purposes.

Transition Planning

Transition planning maps the path from school to adult life — and it starts early.

1

Start Early

Formal transition planning begins by age 14-16; the mindset starts sooner.

2

Cover The Whole Life

Education, employment, independent living, and community participation.

3

Youth-Led & Measurable

Built on the young person's goals, with steps, services, and timelines.

Transition Planning Is About More Than Graduation

Successful transitions prepare young people for life—not just life after school.

Transition planning should include conversations about:

- Employment goals.
- Postsecondary education or training.
- Independent living skills.
- Transportation.
- Financial literacy.
- Healthcare management.
- Community participation.
- Social relationships.
- Recreation and leisure.
- Self-advocacy.

Key Message: Graduation is not the destination—it is one step in your child's lifelong journey toward independence.

Reflection: Which area of transition planning feels most important for your family right now?

Questions Parents Can Ask the Transition Team

Bring these to the table to keep planning on track.

- What are my child's postsecondary goals?
- How were their interests and preferences assessed?
- What independent living skills are being taught?
- Is my child actively participating in the IEP?
- What work experiences are available?
- Has Vocational Rehabilitation been invited?
- What agencies should we contact before graduation?
- What accommodations will my child need after high school?
- Who is responsible for each transition activity?
- When will progress be reviewed?

Nothing About Me Without Me

IEP and 504 meetings are opportunities to practice self-advocacy before adulthood.

Depending on their age, communication style, and support needs, young people can participate by:

- Attending part or all of the meeting.
- Introducing themselves.
- Sharing their strengths and interests.
- Talking about what is difficult for them.
- Identifying accommodations that help.
- Sharing goals for school, work, or adulthood.
- Asking questions.
- Reviewing goals and progress.
- Helping decide what they want to work on next.

Key Message: Don't wait until adulthood to expect self-advocacy. Use today's meetings as practice for tomorrow's decisions.

Reflection: How involved is your child in their IEP or 504 process now? What is one part they could take greater ownership of at their next meeting?

Prepare Your Child To Use Their Voice

Self-advocacy works best when young people have time to prepare.

Before the Meeting

Help your child think about:

- **My strengths:** What am I good at?
- **My interests:** What do I enjoy?
- **My challenges:** What is difficult for me?
- **My supports:** What helps me succeed?
- **My goals:** What do I want to learn or accomplish?
- **My questions:** What do I want the team to explain?

During the Meeting

Encourage your child to:

- Speak or communicate **before you answer for them.**
- Ask for clarification when something is confusing.
- Express agreement or disagreement.
- Talk about accommodations that work.
- Participate in decisions about their goals.

Before, During, and After the Meeting

Self-advocacy works best when young people have time to prepare.

After the Meeting

Ask:

- Do you understand what was decided?
- Do you agree with your goals?
- What are you responsible for?
- Who will help you?
- Is there anything you wish you had said?

Parent Tip

Prepare → Practice → Participate → Reflect

Start small and increase responsibility over time.

Key Message: An IEP or 504 meeting isn't only a meeting about your child. It can become a training ground for your child to learn how to advocate for themselves.

More Responsibility After High School

The system of supports changes when a student leaves IDEA-based special education

In K-12 Special Education

- The school identifies needs.
- The IEP team coordinates services.
- Parents are active decision-makers.
- The school provides required supports.
- IDEA protections apply.

In College or Adult Settings

- The young adult may need to disclose their disability.
- Disability documentation may be required
- The young adult requests accommodations.
- The individual works directly with disability/access services.
- Parents may not automatically receive information.
- ADA and Section 504 protections apply.

The Big Picture: Legal Adulthood

When a young person reaches the age of majority, they generally become the legal decision-maker for their own life unless another legal arrangement applies.

Changes to expect:

- educational rights change
- healthcare decision-making changes
- parents may no longer automatically have access to information
- benefits and services may operate differently
- decision-making supports should be considered based on the person's actual needs

What Parents May Notice At 18?

Be mindful that legal adulthood brings a new set of rights and responsibilities.

At age 18, noticeable changes may include:

- Healthcare providers may seek the young adult's consent
- Educational records may no longer automatically be shared with parents
- The young adult signs their own documents
- Voting eligibility begins
- Benefit/service rules may change
- Families may need releases/authorizations where appropriate

Parents may no longer automatically have decision-making authority or access to records.

Key Message: Families should begin discussing adult rights and support options before age 18.

Decision-Making Support Options

Choose the least restrictive support that fits when a person becomes an adult.

1

Supported Decision-Making

The person keeps their rights and chooses trusted advisors to help them decide. Least restrictive.

2

Powers of Attorney

The person authorizes someone to act in specific areas — and can revoke it. Flexible and targeted.

3

Guardianship

A court transfers some or all decision rights to another. Most restrictive — a last resort.



Least Restrictive First

Start with the most empowering option; use only as much support as truly needed.

Postsecondary Education Pathways

College and training look different — and more possible — than many families expect.

1

Many Doors

Community college, four-year, trade and certificate programs, and inclusive higher-ed.

2

Inclusive Options

Programs designed for students with intellectual and developmental disabilities exist nationwide.

3

New Rules Apply

IDEA ends; students self-disclose and request accommodations through disability services.

4

Build Readiness Now

Self-advocacy, study skills, and independence prepare the path.

MODULE 4 · WORK

Employment Expectations

Integrated work is the expected outcome for most.

- Presume employability — most people with disabilities can and do work with the right supports.
- Explore jobs tied to strengths and interests.
- Supports exist: job coaches, customized employment, and workplace accommodations.
- Early work experiences — chores, volunteering, internships — build the resume.



The Importance of Early Work Experiences

Readiness is built through real experience, over years.

Work readiness can begin through:

- Household responsibilities
- Volunteer activities
- School-based jobs
- Job shadowing
- Internships
- Summer employment
- Community service
- Career exploration
- Learning workplace communication
- Practicing transportation to work

Key Message: Early experiences help young people discover interests, build skills, and develop expectations for employment.



MODULE 4 · BELONGING

Community Participation & Civic Engagement

Some would say a full life includes belonging, contributing, and having a say.

- **Community:** recreation, faith, volunteering, clubs, and friendships.
- **Civic engagement:** voting, speaking up, and shaping local decisions.
- **Participation** builds skills, networks, and a sense of purpose.
- **Accessibility and support** make inclusion real, not just invited.

Your Child's Circle of Support

Independence does not mean doing everything alone—it means directing the support that helps you live the life you choose.

A strong circle of support may include:

Center: Your Child or Young Adult

Family & Friends

- Parents and caregivers
- Siblings
- Extended family
- Trusted friends

Education & Employment

- Teachers
- Transition coordinators
- Employers
- Job coaches

Community Supports

- Center for Independent Living (CIL)
- Vocational Rehabilitation (VR)
- Peer mentors
- Faith communities
- Recreation programs

Healthcare & Other Services

- Medical providers
- Therapists
- Behavioral health professionals
- Case managers (when applicable)

Key Message: The goal is not fewer supports—it is supports that empower your child to make decisions and direct their own life.

Key Message: Who is currently in your child's Circle of Support? Is there anyone you would like to add?

Supported Decision-Making in Everyday Life

Young people build decision-making skills by making decisions—not by having decisions made for them.

Supported Decision-Making may include:

- Discussing options with trusted supporters.
- Asking questions before making decisions.
- Gathering information together.
- Considering the pros and cons.
- Respecting the young person's final choice whenever possible.
- Learning from both successes and mistakes.

Examples:

Instead of choosing for your child...

- ✓ Help them compare two apartments.
- ✓ Review job offers together.
- ✓ Discuss transportation options.
- ✓ Talk through medical decisions using accessible information

Key Message: Support should increase confidence—not replace decision-making.

Reflection: Think of one decision your child could begin making with more support instead of more control.

Questions Before Considering Guardianship

Explore less restrictive options first.

Ask:

- What specific decisions does the person need help with?
- Can the person make decisions with information presented differently?
- Could a trusted supporter help them understand options?
- Would a power of attorney address the concern?
- Could a representative payee help with benefits?
- Can support be limited to one area?
- What rights would guardianship remove?
- What does the young person want?
- Is there a less restrictive option?

Important: Guardianship laws vary by state. Families should seek qualified legal guidance.

Knowing Your Rights Is Only The Beginning

Rights become meaningful when young people know how to use them.

Encourage Your Child To Practice:

- Asking questions.
- Requesting accommodations.
- Explaining what helps them succeed.
- Participating in IEP and transition meetings.
- Understanding important disability laws.
- Speaking respectfully and confidently.

Remember: *Having rights is important.*

Knowing how to exercise those rights builds independence.

Key Message: Self-advocacy transforms legal rights into everyday opportunities.

Discussion: What is one right your child could begin exercising more independently?

Frequently Asked Questions About Adulthood

Rights become meaningful when young people know how to use them.

Many families share the same concerns as they prepare for adulthood:

"What if my child makes a mistake?"

Mistakes are opportunities for learning and growth.

"What if they need support forever?"

Needing support does not prevent someone from living an independent, self-directed life.

"What if they never live alone?"

Independent Living is measured by choice and self-direction—not by a specific living arrangement.

"What if they cannot speak for themselves?"

Communication takes many forms. Every person has the right to express preferences using the methods that work best for them.

"What if I don't know where to start?"

Begin with one small skill, one new responsibility, or one conversation. Independence grows over time.

Key Message: There is no single path to adulthood. Every family's journey is unique.

Rights, Systems & Your Family

Reflect on what to explore next.

- Which right, law, or system was new or surprising to you today?
- Which agency — CIL, VR, or your school transition team — will you contact first?
- What decision-making support approach do you want to learn more about for your family?

Module 4 — Key Takeaways

- ✓ ADA, IDEA, and Section 504 protect access, education, and accommodations.
- ✓ IDEA ends after high school; in adult settings, young people self-advocate for accommodations.
- ✓ Transition planning starts early and covers education, work, and living.
- ✓ CILs and Vocational Rehabilitation are key allies — connect during high school.
- ✓ Choose the least restrictive decision-making support; guardianship is sometimes a last resort.

KEY TAKEAWAY

Know the rights, use the systems, and keep decisions in your child's hands.



MODULE 5

Community Resources & Family Supports

Services, connection, and caregiver wellbeing.

Building a Coordinated Support Team

Many roles, working together around one person.

A young person's support team may include:

- Family members
- Friends and natural supports
- Center for Independent Living staff
- School transition staff
- Vocational Rehabilitation counselors
- Healthcare providers
- Benefits counselors
- Job coaches
- Peer mentors
- Transportation providers
- Housing specialists

Key Message: The young person should be at the center of the team—not surrounded by people making decisions without them.

Supporting Siblings Along The Journey

Brothers and sisters play an important role in building lifelong relationships—but they should not be expected to become caregivers.

Siblings can:

- Encourage independence through everyday activities.
- Include their brother or sister in family experiences.
- Celebrate strengths and accomplishments.
- Learn about disability and accessibility.
- Become lifelong allies and advocates.

Parents can help by:

- Avoid placing adult caregiving responsibilities on siblings.
- Spending individual time with each child.
- Encouraging open conversations about feelings and experiences.
- Recognizing each child's unique strengths and needs.

Key Message: Strong sibling relationships are built through love, respect, and shared experiences—not responsibility alone.

Reflection: How can your family encourage positive sibling relationships while supporting everyone's individual needs?

Practical Living Supports

The everyday supports that make independent living workable.

1

Transportation

Travel training, paratransit, public transit, and ride programs build mobility.

2

Housing

Accessible housing, supported living, roommates, and housing assistance options.

3

Financial Literacy

Budgeting, banking, ABLE savings accounts, and money-management skills.

Transportation Is More Than a Ride

Getting there involves a whole set of teachable skills.

Transportation skills may include:

- Reading a route or map
- Scheduling a ride
- Using paratransit
- Paying a fare
- Recognizing landmarks
- Asking for assistance
- Handling delays
- Using safety strategies
- Knowing who to contact in an emergency

Discussion: What transportation skill could your child begin practicing now?

Community & Family Connection

Connection fuels resilience for young people and parents alike. What connections do you find to be the most beneficial to your unique family experience?

1

Community Organizations

Disability nonprofits, recreation, faith communities, and interest-based clubs.

2

Parent Support Groups

Spaces to share, learn, and feel understood by families who get it.

3

Sibling & Family Support

Siblings and extended family benefit from their own connection and information.

4

Online Communities

Virtual groups extend support beyond geography and busy schedules.

From Programs to Belonging

Participation is more meaningful when young people are not only present—but included.

1

Presence

The person attends the activity.

2

Participation

The person takes part in the activity.

3

Belonging

The person is known, valued, missed, and able to contribute.

Key Message: Community inclusion is not simply being in the room. *It is having relationships, roles, and a sense of belonging.*

Belonging Is More Than Participation

True inclusion means more than simply being present—it means being welcomed, valued, and actively involved.

Community belonging happens when young people:

- Build meaningful friendships.
- Participate in activities they enjoy.
- Feel respected and included.
- Have opportunities to contribute.
- Develop confidence in new environments.
- Are recognized for their strengths.

Families can encourage belonging by:

- Exploring clubs, sports, and recreation.
- Joining disability-led organizations.
- Participating in community events.
- Encouraging volunteer opportunities.
- Supporting leadership experiences.

Key Message: Everyone deserves not only access to their community—but a place where they truly belong.

Discussion: Where does your child feel the greatest sense of belonging today? Where could new opportunities be explored?

MODULE 5 · YOU MATTER

Caregiver Wellness

You can't pour from an empty cup. Your wellbeing is part of the plan.

- Caring for yourself is not selfish — it sustains your family.
- Protect basics: sleep, nutrition, movement, and moments of rest.
- Keep your own relationships, interests, and identity alive.
- Ask for and accept help — model the interdependence we teach.



The Many Forms of Grief That Parents May Experience

Loving your child deeply and grieving unexpected challenges can exist at the same time.

Parents and caregivers may experience grief related to:

- The loss of expectations they once imagined.
- Watching their child face barriers or discrimination.
- Missing milestones or seeing them happen differently.
- Worrying about their child's future independence.
- Feeling isolated from friends or extended family.
- Carrying guilt, fear, or wondering if they have done enough.

Key Message

Grief is not a sign that you love your child less. It is a natural response to uncertainty, change, and the desire to protect someone you love.

Discussion

Which of these forms of grief have you experienced, and what has helped you continue moving forward?

Caregiver Guilt and Self-Care

Caring for yourself is part of caring for your child.

Parents may feel guilty when they:

- Take time away
- Ask others for help
- Feel tired or frustrated
- Set boundaries
- Focus on their own goals
- Cannot meet every need immediately

Remember: Rest does not mean you love your child less.

Receiving support replicates the same interdependence we want young people to learn.

Managing Caregiver Stress

Stress is real and common. Every parent and caregiver needs to know that self-care is not selfish. These strategies help you stay steady.

1

Name It

Notice signs of burnout early — exhaustion, irritability, withdrawal.

2

Share The Load

Delegate, use respite care, and let others contribute.

3

Small Resets

Brief walks, breathing, and moments of quiet add up.

4

Seek Support

Counseling, support groups, and respite are strengths, not failures.

Building a Support Network

No family should do this alone. Activity: Be sure to map out and expand the circle of support around you.

1

Personal Circle

Family, friends, and neighbors who can show up and pitch in.

2

Peer & Community

Other families, support groups, mentors, and community organizations.

3

Professional Circle

CILs, VR, doctors, educators, benefits counselors, and legal help.

Remember:

Seeking support is not giving up independence.

It is using available resources to increase opportunities and success.

Natural Supports vs. Paid Supports

Both have a place in a strong, independent life.

Natural Supports

- Family
- Friends
- Neighbors
- Coworkers
- Faith communities
- Club members
- Community relationships

Paid or Formal Supports

- Personal care attendants
- Job coaches
- Therapists
- Case managers
- Transportation providers
- Agency staff

Key Message: Strong independent lives often include both natural and formal supports.

Why Peer Support Matters

Sometimes the best encouragement comes from someone who has lived a similar experience.

Peer support can help families:

- Learn practical strategies from others
- Reduce feelings of isolation
- Gain confidence through shared experiences
- Discover community resources
- Build lasting friendships
- Feel understood and supported

For young people, peer support can:

- Increase confidence
- Build leadership skills
- Encourage self-advocacy
- Foster independence
- Create meaningful social connections

Key Message: Peer support is one of the core principles of the Independent Living Philosophy because people learn and grow through shared experiences.

Discussion: Who has encouraged your family on this journey? How can peer connections continue to support your child's independence?

Celebrating Progress

What we celebrate, we grow. Mark the steps, not just the destination.

1

Notice Small Wins

Every new skill and brave attempt deserves acknowledgment.

2

Make It Visible

Track growth so the young person can see how far they've come.

3

Let Them Define Success

Celebrate their goals and their milestones, on their terms.

4

Share The Joy

Celebrate together as a family and community — pride fuels persistence.

Resources & Self-Care Check-In

Reflect on support — for your child and for you.

- Which resource from this module will you explore first for your young person?
- What is one support you'll add to your own circle as a caregiver?
- What is one small act of self-care you'll commit to this week?

Module 5 — Key Takeaways

- ✓ CILs, peer support, benefits counseling, and community services can help families build a strong support network.
- ✓ Transportation, housing, and financial literacy make independence workable.
- ✓ Connection through community and parent groups builds resilience.
- ✓ Caregiver wellness is part of the plan — care for yourself, too.
- ✓ Celebrate progress to sustain momentum for the whole family.

KEY TAKEAWAY

Strong support networks — including your own — make independence sustainable.



MODULE 6

Action Planning for Independence

Building your family's plan — and your next steps.

Creating a Family Independence Plan

A simple, living plan built with your young person — not for them.

1

Strengths & Vision

Start with what they can do and the life they want.

2

Goals & Steps

Choose independence goals and break them into doable actions.

3

Resources & Timeline

Identify supports needed and set realistic timeframes to track progress.

The Young Person's Voice Comes First

Start the plan by listening, not prescribing.

Before writing the plan, ask the young person:

- What do you want to learn?
- What would make your life easier?
- What do you want more control over?
- What do you enjoy doing?
- What would you like to do without help?
- What kind of help works best for you?
- Who do you trust to support you?
- What goal feels important right now?

Key Message: The plan should reflect the young person's priorities—not only the family's concerns.

Identify Strengths

Every plan starts from strength. Name what's already working.

1

Skills & Talents

What does your young person do well or enjoy doing?

2

Character Strengths

Persistence, kindness, humor, curiosity — these fuel goals.

3

Supports That Work

Which tools, routines, and people already help them succeed?

4

Ask Them First

Include the young person's own view of their strengths.

Identify Independence Goals

Choose a few meaningful goals — owned by the young person.

1

Across Life Areas

Home, school or work, community, health, and relationships.

2

Youth-Chosen

Prioritize goals the young person actually cares about.

3

Start With A Few

Pick one or two to focus on first — momentum beats overload.

4

Make Them Clear

Define what success will look like so you can see progress.

Turning a Broad Goal Into a Clear Goal

A clear goal names the skill, support, frequency, and progress.

Broad Goal

“Become more independent with money.”

Clear Goal

“Over the next eight weeks, Jordan will use a weekly budget to track spending and save \$10 each week toward a new tablet.”

Broad Goal

“Learn to cook.”

Clear Goal

“By the end of the month, Nia will prepare one familiar lunch using a picture checklist with no more than one verbal reminder.”

Key Message: Clear goals describe the skill, support, frequency, and expected progress.

Develop Action Steps

Turn each goal into small, concrete steps up the Independence Ladder.

1

Break it down

List the small steps between where they are now and the goal.

2

Assign the rung

Decide who does what at each step, gradually shifting responsibility to the young person.

3

Teach and practice

Plan how the skill will be modeled, practiced, and supported.

4

Make the first step tiny

Choose a next step small enough to start this week.

Plan for Barriers Before They Happen

Anticipating obstacles is part of setting up for success.

For each goal, identify:

- What may make this difficult?
- What signs will show frustration?
- What support can be prepared?
- What tool or accommodation may help?
- Who can provide backup support?
- How will we respond to a setback?
- When should we adjust the plan?

Key Message: Planning for barriers is not expecting failure.

It is preparing for success.

Identify Resources Needed

Match each goal to the supports that will help achieve it.

1

People

Family, mentors, peers, teachers, coaches, and professionals.

2

Services & Agencies

CIL, VR, benefits counseling, community organizations.

3

Tools & Supports

Assistive technology, checklists, transportation, and routines.

4

Funding

Benefits, ABLE accounts, VR funding, and community programs.

Set Timelines & Measure Progress

Give goals a timeframe and a way to see how far you've come.

1

Realistic Timeframes

Set gentle target dates — weeks or months — for each step.

2

Track Visibly

Use a chart, journal, or checklist the young person can see.

3

Review Regularly

Check in, celebrate wins, and adjust the plan as life changes.

4

Adjust The Plan, Not The Person

If a step is stuck, change the step — not your belief in them.

Measuring Progress Beyond Perfection

Growth shows up in many ways before full independence.

Progress may look like:

- Needing fewer reminders
- Completing more steps
- Asking for help appropriately
- Trying without being prompted
- Recovering from mistakes
- Making more choices
- Speaking more during meetings
- Using a support tool independently
- Showing increased confidence
- Practicing the skill more consistently

Key Message: Success is not only completing the task alone.

Progress toward greater control also counts.

Creating A Home That Encourages Independence

Independence grows through the environment we create every day.

Families can encourage independence by:

- Offering meaningful choices.
- Encouraging problem-solving before providing answers.
- Expecting participation in household responsibilities.
- Celebrating effort instead of perfection.
- Speaking directly to their child.
- Including their child in family decisions.
- Maintaining high expectations while providing appropriate support.

Key Message: Everyday routines create lifelong habits.

Reflection: Which family routine could better encourage independence?

Encouraging Lifelong Independence

Independence isn't a finish line — it's a direction you keep growing toward.

1

Keep Raising The Bar

As skills grow, offer new challenges and bigger decisions.

2

Expect Growth At Every Age

Learning and independence continue throughout adulthood.

3

Stay A Partner

Your role continues — as ally, coach, and cheerleader, for life.

4

Trust The Journey

Progress isn't linear; keep believing and keep supporting.

Family Commitment

Turn intention into everyday practice.

Complete the statements:

- We will give more opportunities for...
- We will pause before helping with...
- We will practice...
- We will connect with...
- We will listen more carefully when...
- We will celebrate progress by...
- We will review our plan on...

Closing Message: Small changes in everyday routines can create major changes in confidence, skills, and independence.

Final Reflection — Your First Step

Bring the whole training together in one commitment.

- What is the single most important thing you'll do differently after today?
- What is the first, small step you'll take with your young person this week?
- How will you take care of yourself along the way?
- Optional: share your first step with the group or a neighbor.

Bringing It All Together

- ✓ Independence means choice and control, supported by interdependence.
- ✓ Your role grows from protector to partner and coach.
- ✓ Skills, self-advocacy, and person-centered planning start at home.
- ✓ Rights, systems, and least-restrictive decision support open adult doors.
- ✓ Resources, connection, and your own wellbeing sustain the journey.

KEY TAKEAWAY

*Presume competence,
build one rung at a time,
and stay their partner for
life.*

Resources & Where to Start

Independent Living

- Local Center for Independent Living (CIL)
- National Council on Independent Living (NCIL)
- Peer support and skills-training programs

Education & Employment

- State Vocational Rehabilitation (VR) office
- School transition coordinator / IEP team
- Inclusive postsecondary education programs

Rights & Decision-Making

- Protection & Advocacy (P&A) agency in your state
- Supported Decision-Making resources
- Disability rights legal organizations

Benefits & Family Support

- Benefits counseling (SSI, Medicaid, ABLE)
- Parent Training & Information (PTI) center
- Parent support groups and respite care



Thank You

Every step toward independence is worth celebrating.

You are your child's first and most enduring partner in independence. You don't have to have every answer today. You don't have to prepare your child for everything at once. Independence is built one opportunity at a time. Give them a voice. Give them room to try. Give them the support they need. And keep believing that growth is possible.

Questions & discussion welcome · Take the Family Independence Plan home to begin.